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Patient preferences for anxiety and depression screening in cancer care: A discrete choice experiment

Introduction

People living with a diagnosis of cancer often experience high levels of anxiety and depression (A&D), and this has been observed across different demographic backgrounds, cancer types and stages^{1,2}. Comorbid anxiety and depression experienced by cancer patients are strongly associated with poorer quality of life³, poorer survival⁴ and an increased risk of suicide⁵.

In busy cancer services, A&D are often undetected or underestimated⁶, and many patients report unmet needs for psychosocial care⁷. A&D are treatable, and a strong evidence-base for interventions exists^{8,9}. Early identification and treatment of A&D not only results in improved psychological outcomes but also greater cancer treatment adherence, improved doctor-patient communication and fewer clinic calls and visits¹⁰.

Several international and national guidelines exist for the assessment and management of A&D in cancer and general populations¹¹⁻¹⁴. Despite this, few Australian cancer services routinely screen patients for A&D, and if screening does occur, patterns of referral, treatment and follow-up are highly variable¹⁵.

The Psycho-oncology Co-operative Research Group (PoCoG) an Australian Cancer Clinical Trial Group, has developed an Australian first model of psycho-oncology care; The Australian Clinical Pathway for the Screening, Assessment and Management of A&D in Adult Cancer Patients (ADAPT-CP)¹⁵. The ADAPT-CP was implemented across 12 clinical sites in New South Wales, Australia, as a part of the ADAPT randomised controlled trial (RCT)¹⁶. The ADAPT-CP standardises the identification and management of A&D in cancer care. It recommends that all patients who attend a cancer service are routinely screened for

A&D and based on symptom severity allocated into a stepped-care model for treatment and follow-up. This stepped-care model incorporates five steps – from universal care and self-management for those with minimal or mild levels of A&D to specialist mental health care for those with severe A&D, with review and change in step where necessary. Evidence-based recommendations on staff responsibilities, content and timing of interventions, are provided for each step and tailored to available resources.

Formalised routine screening for A&D using a validated screening tool is the first step of the pathway. If screening does not occur, subsequent phases (treatment and follow-up) of the ADAPT-CP may fail to be initiated.

One of the underlying determinants of screening uptake is patient preferences; health services need to be acceptable and convenient for patients¹⁷. Patient preferences for A&D treatments have been explored in the literature, and studies suggest that matching patient preferences has the potential to improve the uptake of A&D treatments. Dwight-Johnson, et al.¹⁸ reported in primary care settings depression treatment was more acceptable when assistance with the logistics of treatment (transportation and telephone consultations) was provided. Lokkerbol, et al.^{19,20} found that patients with A&D preferred face-to-face treatment and shorter waiting times. Even after accounting for age and education, significant preference variations exist for the treatment of A&D. Lokkerbol, et al.^{19,20} highlighted the importance of matching treatments to individual patients to enhance treatment uptake where possible. Hobden, et al.²¹ found that cancer patients' level of concern about depression could influence the type of care (clinician-directed or self-directed) they would like to receive and have noted that this will have implications for depression screening in clinical practice. In the same way, we believe that the uptake of A&D screening could be enhanced in the cancer population by understanding patient preferences. To the best of our knowledge, patient preferences for A&D screening in the cancer population have not yet been explored.

Patient preferences drive uptake of a health intervention, and it is therefore essential to identify features of an intervention that improve uptake ²². This paper uses a discrete choice experiment (DCE) to identify and measure patient preferences concerning screening for A&D in cancer care. DCEs have been previously used to predict the uptake of health interventions in a range of health settings, for example, primary care ²³, palliative care ²⁴ and cancer screening ²⁵.

This DCE aims to determine the features of an A&D screening program cancer patients value most, which can then inform decision-makers about ways to improve the provision of patient-centred care.

Methods

Identification and development of attributes and levels

Attributes and levels were identified through a review of the literature and based on recommendations outlined in the ADAPT-CP ¹⁵.

Medline, Cochrane, Econlit, PsycINFO & PsycARTICLES were searched using medical subject headings and keyword terms: (((discrete choice or DCE or conjoint analysis) or discrete choice experiment* or (valuation and (DCE or conjoint analysis)) and (anxiety or depression)). Only full-text DCE papers reporting results for adults with cancer and published in English between 1999-2019 were included. A total of 142 articles were identified, and 20 studies met the inclusion criteria. A total of 32 attributes were extracted and categorised (see Appendix 1). Only one ²⁶ included attributes concerning A&D screening. We decided to split the delivery of screening attribute used by Dwight Johnson, et al. ²⁶ into two attributes to be able to elicit preferences for (1) The method of screening (online form, pen and paper form, face to face interview, phone call) and (2) The health professional involved (social worker, psychologist, cancer nurse, cancer doctor, general practitioner).

To reflect preferences towards a screening program like the ADAPT-CP, the selection of the attributes were informed by the three components of the ADAPT-CP: (1) Screening, (2) Intervention, and (3) Review and follow-up. Attribute selection was also informed by clinical knowledge and experience from psycho-oncology experts at PoCoG.

Development

An initial list of attributes and levels were presented to and reviewed by health economics experts at the Centre for Health Economics Research and Evaluation, University of Technology and, psycho-oncology experts at PoCoG, University of Sydney.

A choice experiment was then developed in which cancer respondents were asked to consider screening for A&D (the vignette). Participants were then presented with a series of choice sets each describing two alternative screening services, and in each choice set, asked to state their preference.

Cognitive interviews were used to test respondent comprehension and interpretation of DCE attributes^{27, 28}. Cognitive interviews are commonly used when developing DCEs in health²³⁻²⁵. Participants for the cognitive interviews were recruited from two sources: an online panel provider, Stable Research (SR), and from a survey and questionnaires group within a breast cancer support and advocacy group, Breast Cancer Network Australia (BCNA).

An interview schedule guided the interviews and participant comprehension was assessed across four components: (1) comprehension of the attribute item, (2) retrieval of relevant information, (3) use of that information to make a judgment and (4) providing a response²⁹. After completing all choice sets, participants were also asked whether there were any other attributes that would affect their choice.

Seven participants, aged 18 years or older who had a cancer diagnosis, were interviewed.

Difficulties in responding to two of the attributes were due to insufficient context in the vignette and unclear terminology. As a result, changes were made iteratively throughout the interview process; more context was provided in the background and terminology was refined to aid respondent comprehension. All cognitive interview participants reported that they did not consider other attributes to be important in their choices, and that the presented attributes were sufficiently comprehensive.

The final list of eight attributes and their levels is presented in Table 1.

Design and simulation

A main effects design was constructed using two generators and an orthogonal array with 32 options³⁰. This gives rise to 64 choice sets. The design had a D-efficiency of 84.8% for an assumed prior with all entries equal to 0. A simulation study for various initial non-zero priors yielded both small standard errors and ranges for each estimated parameter, demonstrating the design was robust to different prior specifications.

The 64 choice sets were grouped into four blocks of 16 choice sets, and respondents were randomly assigned to one of the blocks. Each choice set comprised a forced choice between two alternatives: screening program 1 and screening program 2. An opt-out option was provided after the forced choice between the two alternatives to identify those who would rather not participate in a screening program all together.

The vignette and an example choice set are presented in Appendix 2 and Appendix 3, respectively.

A pilot study was undertaken with a general population sample (n=77) to ensure the experiment performed as intended. Statistical analysis was conducted using two models: (1) conditional logit model, (2) mixed logit model. As results were consistent with expectations (ordered and in the expected direction), no changes were made to the DCE.

Recruitment and data collection

This study was administered online through the survey platform of Survey Engine ³¹, a survey provider company with experience in administration of DCEs. People with an experience of cancer were recruited using the same sample frames as for the cognitive interviews.

Specifically, participants were recruited from two sources (1) members of the BCNA surveys and questionnaires group and (2) participants in the Stable Research (SR) online panel.

Participants were eligible if they were aged 18 years older who resided in Australia and had a previous diagnosis of cancer. In the case of the BCNA sample, the participants were sent an invitation link by BCNA to complete the survey online. In the case of SR, participants who were eligible were sent a link by SR to complete the survey online.

This study was approved by the UTS Human Research Ethics Committee (UTS HREC REF NO. ETH18-2507) and the BCNA research committee (dated 2nd of August 2019).

Analysis

Descriptive statistics were used to describe the demographic characteristics of the sample.

Mixed logit (MIXL) and latent class (lclg) models were used to analyse the choice experiment responses. Willingness-to-accept measures were also calculated. The analysis was conducted using STATA version 15.

Mixed Logit (MIXL)

The MIXL model relates the probability of choosing an alternative within a choice set to the attribute levels used to describe each option and also allows for the specification of one or more parameters as randomly distributed ³². In addition, the MIXL includes a random error term that adjusts for variations in an individual's preferences ³³.

The MIXL model is outlined in Equation 1, where the utility for individual i associated with choice j in scenario s is:

$$U_{ijs} = \beta X'_{ijs} + (\eta_i X'_{ijs} + \epsilon_{ijs}) \quad \text{Equation 1}$$

where β_i is a vector of coefficients, X'_{ijs} is a vector of explanatory variables, and η_i is a vector of person specific deviations from the mean. The MIXL model estimates a set of mean preference weights and a set of standard deviations of effects across the sample. Interpretation of mean preference weights is made in relation to a base level. The standard deviations indicate variability in the mean preference weights; larger (smaller) values indicate greater (smaller) variability³³.

In both the mixed logit and the latent class models, all attributes except cost and waiting time were dummy coded (categorical), with one level (the base level) being omitted. Cost and waiting time were specified as continuous variables to facilitate estimation of willingness to accept and willingness to wait, as discussed below. Linear and higher order specifications of the cost and wait time variables were tested and these were not statistically significant.

Cost equivalence measures

Based on the MIXL estimates, two cost equivalence measures using the wait time and cost attributes (and associated confidence intervals) were calculated using the “nlcom” command: (1) Willingness-to-wait (WTW) using the waiting time attribute (2) Willingness-to-pay (WTP) using the cost attribute. WTW and WTP are each estimated as ratios; either as the ratio of the value of the coefficient of interest (x) to the negative of the cost or wait time attribute (y). Waiting time and cost were entered in the model as continuous and the linear specification was tested. Interpretation of estimates for each attribute level is made in comparison to the base case. It is important to note that the cost attribute refers to the cost of treatment if required, and therefore it does not represent a willingness-to-pay for screening as such, but more a measure of the relative value of different screening programs. Caution should be applied in interpreting these results because they will be somewhat confounded by the respondent’s prior beliefs about the likelihood of needing follow-up treatment.

Latent class model (llogit)

In addition to the MIXL model, latent class models can further explore preference heterogeneity. The model assumes that classes/groups of respondents exist within the sample, and the preference weights within each class are identical but are also systematically different from preference weights in other classes³³. Within each class, preference weights are estimated using a conditional logit model³³. A user-written Stata module³⁴, *llogit*, was used to conduct this analysis. Demographics of each class were tabulated using *by class: tabulate* in STATA after model estimation.

The optimal number of latent classes were chosen by examining the goodness-of-fit statistics; Bayesian information criterion (BIC) and the Conditional Akaike information criterion (CAIC)³⁴.

Results

Description of the study population

A total of 660 participants started the survey. Of these, 2 were screened out due to age and gender quotas already having been filled, 12 did not meet inclusion criteria, 6 duplicate entries, and 346 were timed out of the survey either by the respondent or the survey system after 15 minutes of inactivity. This resulted in a sample of 294 completed surveys; BCNA (n=130) and Stable Research (n=164). Only respondents (n=294) who completed all 16 choice sets were included in the analysis.

Demographic characteristics of the sample are presented in Table 2. Compared with the general Australian population, our participants were generally older (as expected of a cancer population) and more educated. We also had a high proportion of females, which is to be expected with recruitment from BCNA. Most of the respondents were diagnosed with breast

cancer, and their first diagnosis of cancer was more than 5 years ago. The majority of respondents have normal levels of anxiety (57.1%) and depression (71.8%).

Forty-three per cent of the sample never opted-out of their chosen screening program. Most respondents (63%) chose the opt-out in 4 or fewer of the 16 choice sets they saw in the DCE. Only 8 respondents (3%) always chose the opt-out.

Mixed logit model (MIXL)

Table 3 presents the results of the MIXL. The results indicate a preference for a cancer nurse to conduct face-to-face screening at regular intervals (monthly and every three months) compared with a social worker. Post-screening care and follow-up by the psycho-oncology team is also most preferred when compared with a peer support group. Low cost and shorter waiting time are also preferred. The magnitude of each standard deviation (for eleven out of nineteen attribute levels) is almost equivalent to its corresponding coefficient and are also statistically significant, indicating that variability in individual patient preferences exists³³. All parameters were specified as random, except for cost and waiting time.

Willingness-to-wait (WTW)

The attribute for waiting time was used to estimate a willingness-to-wait. Because this was the wait time to be screened and for follow-up and care, it can be more readily interpreted as a measure of strength of preference for the screening service. Figure 1 presents the willingness-to-wait estimates for (1) health professionals involved in screening and (2) post-screening follow-up and care.

Respondents are most willing to wait to participate in a screening service if a cancer nurse conducts the screening (44.49 days) and least willing to wait for a GP (21.62 days) compared with a social worker. Post-screening, respondents are willing to wait 61.08 days for a

screening service that has a psycho-oncology team in the cancer service compared with a peer support group.

Willingness-to-pay (WTP)

As a secondary measure of willingness-to-accept, the cost attribute was used to calculate a WTP measure. Because the cost attribute related to cost of follow-up rather than screening, it should be interpreted as providing an indication of the value of different screening services rather than a willingness to pay for screening directly. The results are presented in Figure 2 show that people living with cancer place a high value on three aspects of a screening program: (1) The screening health professional, (2) Screening regularity, & (3) care and follow-up post-screening.

The measure of willingness-to-pay is highest (\$156.19) for a screening program that involved screening by a nurse compared with a social worker (base level). WTP for a screening program that involves monthly screening was \$159.77 and for three monthly screening was \$154.77 compared with once-off screening. Follow-up and care by the psycho-oncology team was valued the most at \$214.43 compared with a peer support group.

Latent class analysis

Table 4 presents the results of the latent class model.

Based on the BIC and CAIC, a two-class model was selected to explore class membership further. Four class membership variables were selected: gender (male vs female), type of cancer (other vs breast), panel (SR vs BCNA) and income (< median Australian weekly income vs \geq median Australian weekly income & prefer not to say). These were dummy-coded and included in the latent class model.

With a 2 class model, 73% fall in class 1 and 27% fall in class 2. Compared with class 2, class 1 respondents have higher proportions of those who are female and tertiary educated. Class 1

respondents prefer to be screened by a cancer nurse, whereas those in class 2 prefer a psychologist. Class 1 respondents prefer to be re-screened at regular intervals and even up to 1 year, while class 2 respondents prefer once-off screening. Both classes prefer low cost; however, class 2 is more cost-sensitive compared with class 1. No class membership variables significantly predicted class membership, indicating that there may be other variables that are not captured in this study contributing to class membership.

Discussion

This study reports cancer population preferences for A&D screening programs in cancer care. Whether the aim is to maximise uptake or achieve patient-centred care, our findings provide important new information for successful implementation of routine A&D screening in cancer services. These findings will also give decision-makers the evidence to make informed resource allocation decisions that will not only maximise uptake but are patient-centred as well.

Our results demonstrate that people with cancer on average, prefer a screening program that is routinely offered, done face-to-face with a cancer nurse with follow up care provided by the specialist psycho-oncology team within the cancer service. The latent class analysis revealed 2 classes of cancer patients. Most participants (class 1, 73%) prefer screening to be done with a cancer nurse at regular intervals. While a smaller proportion of participants (class 2, 27%), characterized by higher proportions of tertiary educated females, prefer once-off screening with a psychologist. Both classes prefer low cost. While most participants fit within class 1, there are still more than a quarter that fit within class 2; demonstrating that there are distinct classes with different preferences. On a clinical level, this means that health services should implement a screening program that matches the preferences of class 1 participants, and if possible, flexibility in clinical service delivery should be made available to suit those in class 2. Overall, this reflects a preference for a cancer service that offers integrated mental health

care; whereby both cancer and mental health care can be accessed within one single health service. Cancer patients have a higher willingness-to-wait and to-pay when the screening program involves screening undertaken by an oncology health professional; cancer nurse (WTW= 44.92 days & WTP= \$156.29). Respondents are willing to wait up to 2 months (61.08 days) and have a willingness to pay value of \$214.43 to participate in a screening program that provides follow-up care delivered by a psycho-oncology team within the cancer service.

The preference for integrated mental health care may reflect an individual's desire to simplify their patient experience. Care that is easier to access has been shown to positively influence a patient's decision to undertake treatment^{18, 35}. Existing literature also demonstrates that integrated care is more cost-effective in the cancer context^{36, 37}.

While our findings explore the preferences of people with cancer for A&D screening programs, findings are consistent with the preferences of the general population, for the treatment of A&D. The existing literature relating to A&D treatment interventions reports that people prefer interventions that are conducted face-to-face^{19, 20, 38}, with a nurse³⁹, that are low cost^{35, 40} and where waiting time is minimal^{19, 20}.

To date, this is the first DCE exploring patient preferences towards A&D screening programs in cancer care. One of the strengths of this study is the extensive identification and development process conducted to ensure attribute and level content validity and, its relevance to policy and the target population. Moreover, a pilot study and analysis were conducted to ensure the survey instrument performed as designed before launching with the cancer population. Upon completion of the DCE, cognitive burden was assessed by asking participants to rate from strongly disagree to strongly agree the following statements; (1) "I considered the whole description whilst completing the task" and (2) "I found it easy to

imagine the scenarios". For both statements, majority of the respondents answered agree or strongly agree; 83.17% for statement (1) and 72.49% for statement (2). The results indicate that social workers are the least preferred health professional to conduct screening.

Interestingly, only one participant in sample was being cared for by a social worker at the time of this study. This marked reluctance to be cared for by a social worker may not be an actual preference, but rather an evidence of status quo bias (endowment effect)^{41, 42}, in that respondents prefer what they had previously experienced over a new alternative.

Patient preferences for A&D screening in cancer care are complex and could include a long list of attributes and levels. The attributes and levels included were considered most important to people living with a diagnosis of cancer and was validated through cognitive interviews. Nevertheless, there are other attributes that were identified in the literature search but were not included, such as travel time, and other convenience factors as well as intervention effectiveness.

Recruitment for non-breast cancer participants proved difficult through a panel provider, and future studies could explore other recruitment sources such as a cancer service. Future studies should be aware that respondents recruited from cancer support and advocacy groups could potentially bias the recruited sample, in the case of BCNA, 66% of BCNA respondents have received tertiary education vs 22% in the general population.

Furthermore, this study was conducted with an adult Australian cancer population. Therefore, without further validation, our results may not be generalisable to cancer populations in a different country due to differences in how health systems are organised and operated.

Conclusion

Cancer patients prefer a cancer service that offers integrated mental health care services. To maximise patient uptake, cancer services should implement an A&D screening program that

is routinely offered, delivered by oncology healthcare staff in a face-to-face format, with post-screening follow up care provided by a psycho-oncology team that is embedded within the cancer service. Our findings contribute to an area of limited evidence and can be used to design evidence-based and patient-centred screening services for cancer patients. Health services are resource-constrained and implementing or tailoring services that match patient preferences can be burdensome. However, by doing so, there is potential to improve clinical service delivery and overall health service efficiency.

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